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ABSTRACT

The paper traces developments over the last 30 years in Scandinavia regarding the treatment of individuals with mental retardation. Noted are shifts toward decentralization and integration, with the most radical changes taking place in Denmark. The critical role of voluntary organizations in Denmark, Norway, and Sweden is observed. Operation of service delivery systems is illustrated through a case study of one Norway region's approaches to serving its mentally retarded population. Folk High Schools, designed to ease the transition from adolescence to adulthood, toy libraries, and therapeutic communities in which mentally retarded and nonretarded persons live and work, are three Scandinavian contributions to the field. Cross-national cooperation is evident in many areas related to the handicapped. Among matters of concern cited are generally inadequate employment, lack of personnel, and tightened budgets for social services. (CL)

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Programs, Progress, and Problems in Services for Mentally Retarded Persons in Scandinavia

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Introduction

For the past twenty years or more, the Scandinavian or Nordic countries have been presented to the world as models of a humane and progressive treatment of the mentally retarded. The purpose of this paper is to give a broad outline of the developments that have occurred in Denmark, Norway, and Sweden in the last three decades. Attention will be given to some outstanding and sometimes unique programs and services, and finally there will be a discussion of some of the persistent or new problems that exist in the delivery of service for the mentally retarded. The focus will be on the more severely mentally retarded or developmentally disabled. Finland and Iceland will be only briefly mentioned in the present discussion, although they are considered as belonging to the Scandinavian cultural sphere. Services for the mentally retarded in these countries are very similar to those in the other Nordic countries.

Some brief statistics and general information may be in order. The Scandinavian countries are small. Sweden has slightly over eight millon inhabitants, Denmark and Finland about five, Norway slightly over four, and Iceland less than a quarter millon. The standard of living is among the highest in the world. Social services and health systems are well-developed and have resulted in low infant mortality rates and favorable longevity figures.

The definition of mental retardation is flexible, and classification relies as much on general adaptation as on intelligence scores. The

frequent presence of other handicaps reduces the reliability of formal testing. The percentage of the population that is included in the services for the mentally retarded ranges from 3.5 per thousand in Norway to 5.4 per thousand in Finland.

History of Services

The history of services for the developmentally disabled in the different Scandinavian countries has many common features. During the 19th and first half of the 20th century the mentally retarded were mostly cared for in private and charitable residential institutions. Treatment was of a custodial nature, and the large majority of the handicapped received no help at all. The public assumed little responsibility for their care.

After the Second World War dramatic changes began to take place. The public conscience was aroused. Laws were passed in all the countries requiring the formation of programs and services. The national plans were originally for the establishment of a limited number of central institutions to serve large geographic regions. In Norway, for instance, the law of 1950 mandated the creation of ten regions each with a central residential institution for comprehensive care. These institutions were each intended to serve several hundred patients. It is important to keep in mind, in view of the considerable criticism that has been leveled against these institutions in subsequent years, that for the time they were sometimes models of humane and progressive treatment. Good examples are the Children's Hospital and the adult

center Lillemosegaard in Copenhagen. It was places like these that gained worldwide attention in the 1960's and that prompted so many favorable accounts in the professional literature (Clark & Clark, 1970; Kugel & Wolfensberger, 1968; Lippman, 1972; Vail, 1968). Many of the ideas related to normalization were put into practice in these programs years before they were enunciated as formal governmental policy.

In the 1970's the principles of normalization became firmly established as a philosophy of treatment for the mentally retarded. The movement was spearheaded by Bank-Mikkelsen, the head of the Division of Mental Retardation Services in Denmark. Consistent with his view that the handicapped should be served by the same programs that other people use, he recommended the dissolving of his own agency. There was throughout Scandinavia a major shift in the direction of decentralization and integration. The most radical changes have taken place in Denmark. The law of 1980 has placed all responsibility for social assistance upon the 275 municipalities in cooperation with the 14 county administrations. In Sweden, the policy of integration has led to many imaginative approaches, such as integrated apartments (inackorderingshem) and small, family-style student homes (elevhem) where young people from the country stay during the week, while attending school in the cities. Recognizing the need for residential and sheltered care for the more severely disabled, the Swedes, as well as the other Scandinavian governments, have gone to great lengths to turn some of these segregated placements into communities where the handicapped can live with dignity and fulfillment.

Voluntary Organizations

In Scandinavia, the voluntary organizations of and for the disabled serve an important role in the formulation and implementation of services for the handicapped. They exercise their functions in several direct and indirect ways which are different for each country. In Denmark, for some reason, it is difficult for a governmental agency to purchase property. According to the national president for the Danish parent organization for the mentally retarded, it is common practice for the association to assume ownership of a facility. It is then rented to the agency which has responsibility for the program.

In Norway, on the other hand, the government is sometimes hesitant about initiating a needed program. The voluntary organization may therefore start it, and when it has proven its effectiveness, the public authorities often take it over or runs it jointly by providing most or all of the operating expenses. In that country, the Red Cross has made important contributions to improvement of services for the developmentally disabled. This organization owns and runs several schools, day care centers and rehabilitation facilities. The Lions Clubs have added greatly to the enrichment of the life of the mentally retarded. Among other things, the Lions Clubs are the backers of the traditional national arts festival "Vi Vill" (We Will) which brings together in Oslo about a thousand retarded artists from all over the country for several days of joyful celebration and display of their talents in the visual arts, music and drama (Thorsheim, 1979).

In Sweden, the handicap councils have considerable influence on program development. Sweden is divided into 24 counties and 278 local municipalities, which administer most of the programs for the handicapped. Serving as an advisory body to each of the counties and municipalities, there is a handicap council. It is usually made up of about a dozen members, each of whom represents one or several disability groups or organizations. The association for the mentally retarded is one of the four most strongly represented groups on these councils. There is also a National Council for the Handicapped consisting of 18 members appointed by the government (Gardestrom).

In Denmark, the parents and the parent organizations have had and continue to have a powerful role. Until the recent dissolution of the Division of Mental Retardation Services, a parent had by law a seat on the national as well as the regional administrative boards. With the 1980 transfer of all the responsibility for the education and care of the handicapped to the municipalities, two more members have been added to the local school boards. They are elected by and represent the parents ofthe handicapped students served by the school (Skov Jørgensen, 1982).

A Regional Service Program

The service delivery systems vary greatly from one country to another and even within one country. Local initiative and private efforts make their impact on the programs. The region of Ostfold in Norway may serve as an example of how the systems work.

After the enabling act of 1950, several humanitarian organizations together with the regional and state authorities formed a committee to make plans for a central institution to house about 400 of the most severely mentally retarded in the region, which was a large majority of those estimated to need mental retardation services. With funds collected by the participating associations, contributions from local authorities and low-interest loans from the state, land was bought and contruction began. Eventually 12 pavillions or houses were completed with rooms for about 150 clients, both children and adults. Other structures included administrative and service buildings, a school, facilities for vocational training, sheltered workshops, and club activities, together with apartment buildings and houses for the staff.

The shift in public policy towards decentralization and integration in the 1970's brought a stop to expansion. Efforts were now made to keep the handicapped in their local communities and to bring the services to them. The region was divided into five districts that at present accommodate about 300 clients.

The district of Fredrikstad serves about 100 handicapped individuals, about half of them are in preschool centers or in schools. Some are partially integrated in regular schools. The rest are in vocational training or sheltered employment. The district has secured a new building ideally suited for this purpose. Another acquisition is a house that contains small apartments for about ten clients who are learning independent living. The house also provides respite care.

The function of the central institution is limited to caring for the most severely disabled and the physically ill. However, it also serves as an administrative and informational center for the region, carries out assessment of referrals, conducts research, and coordinates and supervises the activities in the district.

Ragna Ringdal Day Center

In 1950 the Support Association for the Developmentally Disabled was established to serve the metropolitan area in and around Oslo. Its first task was to build a day care facility for about a hundred clients. The Ragna Ringdal Home was the first day care center for the more severely mentally retarded in Europe. It has remained a pioneer in education and care ever since and has especially served as a model for the implementation of the principles of normalization. Activities of daily living and community involvement are a central part of the program as are all the arts. The students are well known throughout the country for their performances in music, song, drama, and poetry reading.

Over the years the Center has expanded both its facilities and functions. New schools and sheltered workshops have been built and vacation houses have been acquired. Travel is an important part of the educational offerings and it includes trips to foreign countries. Respite care is available, and vacations are even arranged for the mothers and non-handicapped siblings to reduce or avoid family stress.

The Folk High School

The folk high school is a uniquely Scandinavian institution designed to help young people in their transition from adolescence to adulthood and to provide them with academic and social skills as well as ethical values and training in citizenship. There are at present about 350 such schools in operation. The schools are residential, and they are usually located in attractive surroundings in the country. The students stay for a year, and the average enrollment ranges between 50 and 100.

A few of the folk high schools are especially designed to meet the needs of handicapped youth. Norway has five such schools. One of them, the Peder Morset Folk High School, was established in 1976 to serve primarily the mentally retarded. It is funded by the local and state rehabilitation services and has a capacity of 40 handicapped and 24 non-handicapped students.

Best known internationally is probably the Kjesäter Folk High School in Sweden. It is sponsored by the Swedish Scouting Association. The school has a regular enrollment of 50 young people interested in the creative arts, about 30 mentally retarded, and a smaller number of deaf and hard-of-hearing students. In addition, the center provides the setting for a two-year training program of recreation leaders. Kjesäter also offers shorter courses for Scout leaders for the handicapped and hosts many workshops related to children and youth with special needs. Follow-up studies of mentally retarded who have attended the folk high school have shown substantial improvements in self-

esteem and social adjustment.

The success of the program at Kjesäter has inspired similar developments in Denmark. The hostel for developmentally retarded at Spaniensgade in Copenhagen has within its structure created a folk high school attended by 24 young men and women. The curriculum included general academic subjects, skill development for daily living, drivers' training, and experiences in the arts.

The folk high school movement has never taken roots in other countries, but the ideas and ideals behind it may be relevant to other cultures with different social and economic systems.

Lekoteks or Toy Libraries

Another educational invention emanating from Scandinavia is the lekotek or toy libraries services for the handicapped. The first one was started by Evy Blid and Karin Stensland Junker in Stockholm in 1963. The lekotek actually has a complex and sophisticated function. It provides educational counselling and assistance for families with preschool children who have physical, psychological and social handicaps. It promotes knowledge, gives advice and support as regards the child's development and is a link in the habilitation of handicapped children. The staff cooperates with other agencies involved with the child and serves in a consultative capacity with these authorities. One function of the lekotek is to advise parents with regard to educational toys and to loan them free of charge.

The innovation of the lekotek has had an enormous response in

Scandinavia and throughout the world. In Sweden, there are now 65 lekoteks with a total enrollment of 4,000 children. That is about one percent of the pre-school population. The average lekotek has three staff members and serves 60 children. The major handicap encountered is mental retardation. Most of the centers are financed by the county or the municipality, but some receive their support from the parent associations, Red Cross, or the local school systems.

In Norway, there are currently 136 lekoteks. They are fully funded by the national board of education and are attached to the office of psychological services in the local school districts.

There are no statistics about the number of lekoteks in Denmark, but in Finland there are toy libraries in over 300 communities. Iceland also has several. Another indication of the international interest in this Scandinavian model for early intervention is the fact that at the 1981 International Conference of Toy Libraries held in Stockholm, representatives from 28 nations were present.

Therapeutic Communities

In Sweden the anthroposophic principles of Rudolf Steiner (Healing Education, 1974) have had a considerable impact on the programming for the more severely disabled. The approach, which is called curative education, is based on the transendental or spiritual value of all human beings. The anthroposophists believe that regardless of the severity of the handicap, the personality of the child is essentially intact and can be guided

in its unfolding through proper medical attention, education, close family relationships, meaningful community participation, work, art, leisure, and worship.

Most of the anthroposophic acitivities in Sweden are located in or around the town of Jarna about 20 miles south of Stockholm.

The Steiner schools and communities provide education and treatment for a substantial percentage of the most troubled children in Sweden. Because of their superior quality of care they are also highly regarded by the Swedish people. During an exhibit of anthroposophic education in Stockholm several years back 35,000 people attended.

In Norway, the village of Vidarasen has captured the attention and affection of the people. Every Christmas high school students sell candles made at the village and the profit which generally amounts to $100,000 is donated to the village for new construction. Life at Vidarasen is based on the Camphill principle. Normal and handicapped people live together in a spirit of equality. Arts and crafts products are sold in the village shop as well as in fashionable stores in the capital. Baked goods from its biodynamic farm are in great demand in the surrounding towns. Other Camphill villages are in different stages of development.

In Denmark, the L'Arche movement, founded by the Canadian Jean Vanier, has established itself. A small community has been built in Elsinore where mentally retarded and non-handicapped adults live and

work together as families in a spirit of Christian love and mutual respect.

Nordic Cooperation

The Nordic countries work closely together in many areas related to the handicapped. In 1976, the Nordic Committee on Disability was established. It is a coordinating and joint cooperative body under the Nordic Council of Ministers. In the area of research, the Committee publishes annually an English language report on all current projects, either in progress or recently completed ("Registration", 1980).

Another example of cross-national cooperation was the formation in 1978 of a Nordic Committee on the Developmentally Disabled. Its present focus is on the improvement and dissemination of instructional materials and other helping devices for the mentally retarded.

Problems and Concerns

In spite of the high quality of services, for the mentally retarded in Scandinavia and the momentum for progress that is still going on, there are several matters of concern.

1. One sometimes finds a contrast between the theoretical percentage of developmentally disabled qualified for help, and the actual number served. In spite of highly developed health services and child-find systems, it si believed that many needy individuals remain undetected.
2. Employment of the handicapped, either in sheltered workshops or on the open market, is generally inadequate. Much could

be learned from the progressive practices in some other countries, such as France and the Netherlands.

3. Many programs suffer because of lack of personnel. Insufficient staff has resulted in overwork, fatique, and discouragement. There have been reported incidents to mistreatment of clients, which has been traced to employee shortage and burn-out.
4. A related problem is limited professional training and skills among the employees which may result in inappropriate handling and treatment of clients.
5. Decentralization has also raised the question that small, local communities may not have the quality of specialized services that is available in the larger regional institutions. In addition, it has been feared that the programs will be more uneven in character when they are dependent on the financial resources and initiative of the individual municipalities.
6. The deterioration of the world economic situation has affected the Nordic countries, sometimes quite severely. The philosophy of the welfare state which has been dominant for the past 35 years has also been challenged by recent more conservative administrations. As a result, budgets for social services have been tightened. There is among parents and professionals anxiety about what the future will hold.

Because of the conflicting currents and counter-currents between moving forward and pulling back it is difficult to predict the future directions of services for the mentally retarded in Scandinavia. New circumstances arise, and yesterdays' solutions are often tommorow's problems. But judging from the deep sense of justice and compassion for the weak that are the heritage of the Nordic people they shall beyond doubt continue their progress in this field.

References

Clark, M.J. and Clark, K. (1970) Scandinavian programs for the mentally retarded: How they work. U.S. Department Health, Education and WElfare. Office of Education, Washington, D.C.

Gardestrom, L. (1981) Handicap councils: A Swedish experiment. In K. S. Miller and L. M. Chadderdon (eds), Participation of people with disabilities: An international perspective. pp. 58-73. University Center for International Rehabilitation, East Lansing, Michigan.

Healing education based on anthroposophy's image of man. (1974). Verlag Freies Geistesleben, Stuttgart.

Kugel, F. B. and Wolfensberger, W. (eds), (1968). Changing patterns of residential services for the mentally retarded. President's Committee on Mental Retardation, Washington, D.C.

Lippman, L. (1972). Attitudes towards the handicapped. A comparison between Europe and the United States. Charles C. Thomas, Springfield, IL.

Registration of Nordic projects relating to disability (198). The Nordic Committee on Disability, Stockholm.

Skov Jorgensen, I. (1982) Denmark. In D.G. Tate and L. M. Chadderton (eds). Independent Living: An overview of efforts in five countries: Denmark, Federal Republic of Germany, Yugoslavia, Costa Rica, and Japan. pp. 7-29. University Center for International Rehabilitation, East Lansing, Michigan.

Thorsheim, M.J. (1979) Normalization in Norway. Education Unlimited. 1, (5) 26-29.

Vail, D.J. (1968). Mental health systems in Scandinavia. Charles C. Thomas, Springfield, IL